

Isle of Man provides unique forum for presenting health care grievances

Caroline Richmond

Résumé : Caroline Richmond nous parle de l'île de Man enchantée, état souverain indépendant situé au large des côtes d'Angleterre qui offre à ses résidents un recours sans pareil en cas de grief. Une fois l'an, le jour de Tynwald, les insulaires peuvent soumettre tous leurs griefs à un comité. Des parents se sont prévalus de ce recours récemment pour se plaindre des soins de santé prodigués à leur fils.

Set in the middle of the Irish Sea, the Isle of Man is an independent sovereign state ruled by the Lord of Man, who for the last few hundred years has been the English Sovereign.

It has the world's oldest parliament, Tynwald, and also offers a unique form of redress for people with complaints. Once a year, on Tynwald Day, residents can "Petition for Redress of Grievance." A few years ago a Manx family did just that over a case of chronic fatigue syndrome.

In 1988 the island's health services earned headlines in England when the *Independent* ran a feature

about "a family's 5-month legal battle to have their sick son correctly diagnosed and returned home." This was followed by lurid headlines such as "Held helpless in a hospital ward" and "Families crushed by undue legal force". The articles and a television program reported on a mute, paralysed boy who had been "snatched" from his family and admitted to hospital, where he was subjected to various assaults. It was alleged that he had been thrown into a swimming pool even though he could not swim, forced to feed himself when he was too weak to do so, and forced onto a ghost train at a fun fair. The child, then aged 13, is Ean Proctor, and his illness is chronic fatigue syndrome (CFS). Those with the syndrome like to call it myalgic encephalomyelitis, a serious viral neurologic illness.

When the Proctors petitioned for redress in 1989, they made several allegations of serious professional misconduct. A commission was appointed and a report was published in 1991. Unfortunately for the Proctors, it vindicated the long-suffering health care workers who had cared for their son and revealed that the family's allegations were a parody of the truth.

Apparently Ean was often kept home from school for illnesses that were trivial or unduly prolonged. When CFS developed at age 11, he

was kept home from his new school, and over 18 months lost 20 kg. When he was admitted to hospital for observation, the ward sister said "he had a transparent look and the aroma of death. A cold would have taken him." He was transferred to the Alder Hey Children's Hospital in Liverpool, where a neurologist diagnosed CFS.

He was discharged by his parents, who took him to relatives in Kent, and it was here that he became mute, a condition that lasted 6 years. They had him admitted to a London neurologic hospital but he was transferred to the Great Ormond Street Children's Hospital; his parents discharged him because they objected to him being in a psychiatric ward, having passive physiotherapy to prevent contractures, and being fed well. They objected that he was not receiving a "yeast-free diet." They took him back home to the Isle of Man, where he was eventually made a ward of the court and admitted to hospital for rehabilitation. During this stay, and afterwards, he was under the care of a North Wales pediatrician approved of by his parents; the doctor had convinced the Myalgic Encephalomyelitis Association that he "believed" in the illness as an organic entity. The pediatrician encouraged Ean's rehabilitation, saying that if there was no progress in 6 months he would call in Manchester

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University's professor of child psychiatry, David Taylor, who is also a visiting professor at McMaster University.

The commission's report showed that the island's child care services had acted well. Ean regained weight rapidly during his stays in hospital and lost it each time his parents took him home. Commissioners saw videotapes of Ean eating and noted that he was doing so without undue difficulty. They saw a tape of him in the hydrotherapy pool, and it seemed a pleasant and helpful activity. They accepted the evidence of a physiotherapist and a nurse who reported that they had taken Ean, on their own time, to a fun fair. He had indicated by smiling and nodding that he wanted to go, had chosen the ride on the ghost train, sat between the two of them, and came out laughing. He returned home, where he had the help of a home tutor who worked closely with the pediatrician.

the extent of not defending themselves against libel. I'll offer a final fanfare for the child health care services on the Isle of Man. Thirty years ago the infant mortality rate was 30 deaths per 1000 infants. Today it is virtually zero.

The island's health service is similar to the British National Health Service, with which it has close informal ties. The 70 000 residents are served by about 100 doctors, including 40 general practitioners. Some are Manx-born; the others, called "come-overs," need a work permit. These are freely available to only a few professions, as the island has virtually full employment. The island's consultants have a heavy on-call load because there are few junior physicians. Salaries and conditions of service are similar to those found in Britain. Patients with difficult problems are sometimes sent to Manchester or Liverpool, and the postgraduate centre has a regular

km² — and from the top of Snaefell (620 m) there are fine views of the highest mountains in England, Scotland, Wales and Ireland. Motorcycle races are held every spring, with roads being closed for the event. There are usually many injuries and deaths are common. The Accident and Emergency Department at Noble's Hospital in Douglas works flat out dealing with injured racers, assisted by Royal Air Force trauma specialists who gain valuable experience. The island, which has no seat-belt laws, has *laissez-faire* attitudes about drinking and driving, and speeding. These add to the annual death and injury toll.

Islanders appreciate their health services. Dr. Anne Lee, a neonatal pediatrician married to a general surgeon, says they are always collecting money for good causes: if the hospital needs expensive equipment, funds are raised. An example was the purchase of a hyperbaric oxygen chamber following a diving fatality; there hasn't been a case of aeroembolism since and the facility now needs new capital and income. The island's physicians are being castigated for not backing this cause.

For travellers, the Isle of Man is a delightful place. It has its own stamps, coins and banknotes, beautiful scenery, sandy beaches and a horse-drawn tram that runs across the 3.2 km of Douglas seafront. The lamb and dairy products are delicious. Manx scallops and kippers are a speciality that earn export revenue. As for Manx whiskey, the less said the better.

And what about Manx cats? These tailless creatures, once the common farm cats of the island, are now rare. Elsewhere, they have become a recognized breed shown at cat shows.

Although this is bad news for the cats, they are beneficial to humans. Every litter has one or two paralysed kittens, which veterinarians discovered have spina bifida. Thus, they provide an animal model for research on human disease. ■

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He eventually started speaking again and has now caught up with his studies, and has a normal set of teenage interests.

The Proctor affair has caused considerable pain within the island's child services, and a damaging public backlash. Far from being pleased with Ean's recovery, the Proctors are still trying to get the commission's report overturned and feel they deserve compensation. The island's doctors have been worn down by the lobbying of the local Myalgic Encephalomyelitis Association, even to

series of speakers from around the British Isles.

Yet to come to the Isle of Man is to step back in time. Hanging and flogging are still on the statute book, and abortion is banned, even when there are strong medical indications; homosexuality was not decriminalized until 1992. There is some enthusiasm for hanging and flogging but almost no homophobia. One person is on death row but it is a virtual certainty that he will not be hanged.

The island is small — only 575